#### UCLA Presentations

**Title** Beyond Privacy: The Emerging Ethics of Data Reuse

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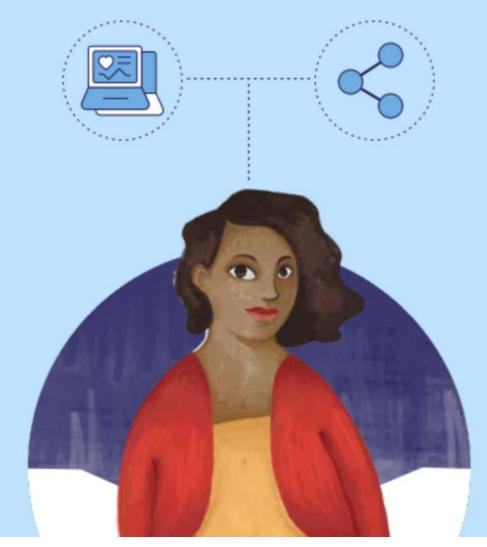
2018-09-16

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### UCLA Center for Knowledge Infrastructures





## Beyond Privacy: The Emerging Ethics of Data Reuse



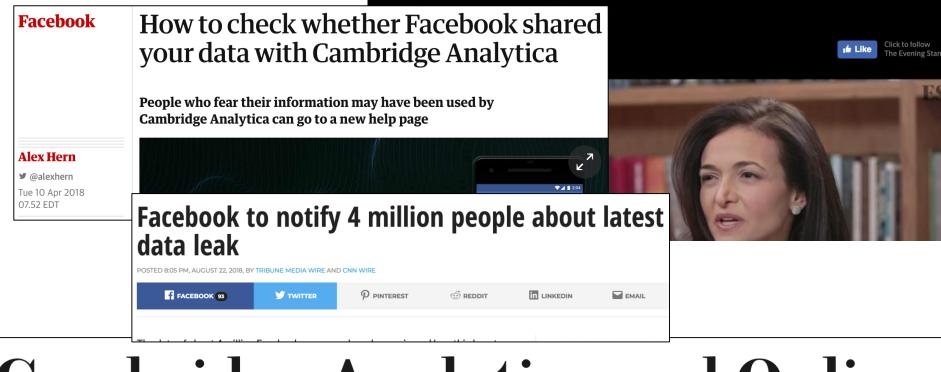
Trusted evidence. Informed decisions. Better health.

Image credit: All of US project, https://allofus.nih.gov/

## WHO GETS ACCESS TO RESEARCH DATA? AND WHO GETS TO DECIDE?

News World

Facebook Cambridge Analytica scandal: Sheryl Sandberg apologises for 'big mistakes'



## Cambridge Analytica and Online Manipulation

It's not just about data protection; it's about strategies designed to induce addictive behavior, and thus to manipulate

#### Tuesday, September 4, 2001

www.thisisgwent.co.uk

1284901

Anguish: Mother finds hospital has baby's tissue samples I'm grieving again for my stillborn son

#### By Rebecca Hughes

A MOTHER discovered tissue samples from her stillborn baby are being held at a Gwent hospital more than eight years after his death.

Rhosalyn Hawkins, 36, of Heol Hamelin, Abergavenny, gave birth to Ethan at Nevill Hall Hospital, Abergavenny on June 13, 1993. He weighed 6lb 1202 and was stillborn.

After initially refusing to allow a post-mortem examination she agreed, and it showed Ethan died of natural causes.

"Ethan was buried with my grandparents at Llanfoist cemetery," she said.

"I was watching a television programme about organ and tissue retontion recently and it made me think. I always believed this sort of thing would not happen at Nevill Hall.

"But I decided to ask, and I rang the patient liaison officer at the Royal Gwent Hospital, Newport.

"Three weeks later I had a letter from Martin Turner, the chief executive of the Gwent Healthcare NHS Trust, confirming some very small tissue samples were taken at the post mortem for further examination, and these are still beingheid at Nevill Hall."

In his letter, Mr Turner also explained organs or tissue samples may be sent away for a second opinion, for teaching or as part of a research project, or to contribute to improved medical treatment.

But Ms Hawkins said she felt she was back to square one in the grieving process.

"I was devastated when I found out because I thought I had buried him whole,

"It's like burying another child. I just want other parents who may have been in the same position as me to know that this practice of retaining tissue is happening."

A leaflet by the Retained Organs Commission says retaining tissue is not illegal, but concerns following organ retention means the legal framework is being reviewed to clarify when material should be kept and for how long.

The leaflet adds: "Following a hospital post mortem, performed with the agreement of relatives, it

is now accepted that their consent or otherwise to the retention of organs or blocks and slides should have been obtained at the time." A spokesman for the Gwent Healthcare NHS Trust said: "The spossible.

"But it is important to underline that the trust acted within policies and practices accepted throughout the country. New guidelines are now being considered." • Editorial comment: page 12



DEVASTATED: Rhosalyn Hawkins holds a picture of her stillborn son, Ethan James Jorge, Tissue samples

from Ethan's body are being held at Nevill Hall Hospital, Abergavenny



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# 'This is just the beginning': Using DNA and genealogy to crack years-old cold cases

Police are harnessing consumer DNA sites to solve old murders, which could spur a massive clearing of unsolved crimes.

by Kate Snow and Jon Schuppe / Jul.18.2018 / 4:30 AM ET



## Genealogy databases and the future of criminal investigation



SHARE

Natalie Ram<sup>1</sup>, Christi J. Guerrini<sup>2</sup>, Amy L. McGuire<sup>2</sup>

+ See all authors and affiliations

Science 08 Jun 2018: Vol. 360, Issue 6393, pp. 1078-1079 DOI: 10.1126/science.aau1083



#### Modeling 3D Facial Shape from DNA

Peter Claes<sup>1</sup>, Denise K. Liberton<sup>2</sup>, Katleen Daniels<sup>1</sup>, Kerri Matthes Rosana<sup>2</sup>, Ellen E. C Laurel N. Pearson<sup>2</sup>, Brian McEvoy<sup>3</sup>, Marc Bauchet<sup>2</sup>, Arslan A. Zaidi<sup>2</sup>, Wei Yao<sup>2</sup>, Hua 1 Gregory S. Barsh<sup>4,5</sup>, Devin M. Absher<sup>5</sup>, David A. Puts<sup>2</sup>, Jorge Rocha<sup>6,7</sup>, Sandra Beleza Rinaldo W. Pereira<sup>9</sup>, Gareth Baynam<sup>10,11,12</sup>, Paul Suetens<sup>1</sup>, Dirk Vandermeulen<sup>1</sup>, Jen James S. Boster<sup>14</sup>, Mark D. Shriver<sup>2</sup>\*

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#### The Journal of Politics

The Journal of

Politics

Vol. 73, No. 1, Jan. 14, 2011 / A Genome-Wide Analys...

#### JOURNAL ARTICLE

#### A Genome-Wide Analysis of Liberal and Conservative Political Attitudes

Peter K. Hatemi, Nathan A. Gillespie, Lindon J. Eaves, Brion S. Maher, Bradley T. Webb, Andrew C. Heath, Sarah E. Medland, David C. Smyth, Harry N. Beeby, Scott D. Gordon, Grant W. Montgomery, Ghu Zhu, Enda M. Byrne and Nicholas G. Martin *The Journal of Politics* Vol. 73, No. 1 (Jan. 14, 2011), pp. 271-285

Published by: <u>The University of Chicago Press</u> on behalf of the <u>Southern Political Science Association</u> DOI: 10.1017/s0022381610001015 https://www.jstor.org/stable/10.1017 /s0022381610001015 Page Count: 15

# 2018 APSA Annual Meeting & Exhibition

SHORT COURSE

HIGHLIGHT

Genomic Data and Models for Political Science

#### Al that can determine a person's sexuality from photos shows the dark side of the data age

Devin Coldewey @techcrunch / Sep 7, 2017

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## More data, More Open, More Troubles.

## From HYPOTHESIS-DRIVEN RESEARCH

- Vetted research questions;
- "Results data" shared with publications;
- "Raw data" shared within trusted colleagues;
- Use of traditional Informed Consent;

Scientists control access and reuse of the raw, individual-level data they collect.

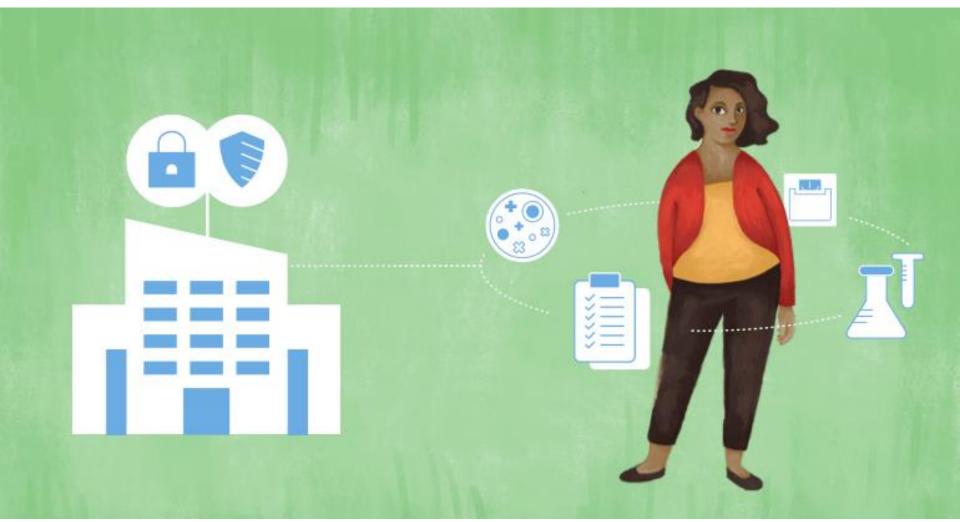
## To HYPOTHESIS-FREE DATASETS

- Idea of research data as "fungible" goods;
- "Raw data" made available on open repositories, for reuse by the science community at large;

Scientists DO NOT control access and reuse of raw, individual-level data they collect.

## Repurposing hypothesis-free open data: Regulating Access as a ITERATIVE PROCESS

## HOW TO CONTROL ACCESS TO OPEN **HEALTH DATA?**



#### Image source: NIH's All of US website

## 1 – Do not control

- Benefits in exchange of unrestricted reuse of data
  - Shared economic benefits with the patients;
  - Or to provide access to treatments and health care.
- "Solidaristic" approaches
  - Participants are willing to risk some harm for the benefit of others.
- Do not control access, but tax secondary reuses of the data

## 2 – Distributed control

- Keep the donors in the loop: inform participants about research studies, including findings and discoveries, that use the donated data.
- Provisionary reuse: give donors the option to pull out their data from a repository if a misuse occurs.
- Distributed responsibility: Have an external and independent party to supervise the moderation process.

## **Questions for Discussion**

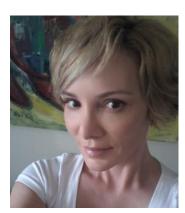
- Who gets to decide how and when to reuse open data?
  - Who should be responsible for decisions about access and reuse?
  - What is the role of the data donors in regulating access to data?
- When should research data be shared within closed collaborations, and when can these be made openly available?
- As data users, what kind of factors should we take into consideration when reusing open data?
- What are the technical challenges of moderating access and reuse of bio open data?

#### UCLA Center for Knowledge Infrastructures





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